

Virginia I. Jones Alzheimer's Disease and Related Disorder Council

Meeting Agenda for January 6, 2014

- I. Open Remarks and meeting minute approval
 - a. Delegate Pena-Melnyk thanked council members for their participation.
 - b. The meeting minutes from the November 20, 2013 meeting were approved to include two corrections.
 - c. Bangwha Lee Casado – who called into the first meeting – introduced herself to the group.
 - d. Robert Egge from the National Alzheimer's Association introduced himself to the group. He will be presenting the National Plan to the Council.
 - e. Absent members: Tonis Paide
- II. Administrative matters
 - a. Staff informed members of the Council website that has been created by the Department of Health and Mental Hygiene. The Council website can be accessed at: <http://dhmh.maryland.gov/SitePages/Alzheimers%20Council.aspx>
 - b. The Council has a google group created where they can share information between meetings. The google group is open to the public and staff provided instructions for accessing and posting to the google group.
- III. Presentation on the Alzheimer's National Plan
 - a. Robert Egge, Vice President of Public Policy for the National Alzheimer's Association discussed his professional background with the group. He worked on an Alzheimer's study group in Washington, DC and joined the Alzheimer's Association in 2009 to work on the creation of the national plan.
 - b. Rob provided an overview of what was occurring at the federal level, as well as context for what states are doing. In 2010, Congress unanimously passed bipartisan legislation – the National Alzheimer's Project Act (NAPA) – calling for the creation of a national strategy to address the Alzheimer's crisis. On May 15, 2012, the U.S. Department of Health and Human Services released the first-ever National Plan to Address Alzheimer's Disease. This Plan will help the more than 5 million Americans living with Alzheimer's and their families today and has the potential to change the trajectory of the disease in the future.
 - c. When crafting the national plan, input was sought across the country about what the plan should address. Ten major challenges were reported:
 - i. A lack of public awareness
 - ii. Insufficient research funding

- iii. Difficulties with diagnosis
 - iv. Poor dementia care
 - v. Inadequate treatments
 - vi. Challenges facing diverse communities
 - vii. Challenges facing those with younger-onset Alzheimer's
 - viii. Unprepared caregivers
 - ix. Ill-equipped communities
 - x. Mounting costs
- d. Five Key Policy Implications came from this:
 - i. Increase public awareness
 - ii. Accelerate research
 - iii. Improve care, starting with diagnosis
 - iv. Build long-term support, starting in the home
 - v. Change for all
- e. The National Alzheimer's Plan was released by the US Department of Health and Human Services on May 15, 2012. The National Alzheimer's Plan has 5 major goals:
 - i. Prevent and Effectively Treat Alzheimer's Disease by 2025;
 - ii. Enhance Care Quality and Efficiency;
 - iii. Expand Supports for People with Alzheimer's Disease and Their Families;
 - iv. Enhance Public Awareness and Engagement; and
 - v. Improve Data to Track Progress
- f. Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025
 - i. The National Alzheimer's Plan calls for several actions to help address the Alzheimer's disease crisis. First, it sets a goal of preventing and effectively treating Alzheimer's by 2025.
 - ii. Second, on top of existing Alzheimer's research funding levels, it calls for an additional \$50 million in 2012 for Alzheimer's research – which the Administration provided – and it proposes an additional \$80 million for research in fiscal year 2013. Alzheimer's disease is inadequately funded in comparison to research funding for other diseases. The Alzheimer's Association is hopeful Congress will become more engaged in providing resources.
 - iii. Third, this goal calls for an international research conference, which was held by the National Institutes of Health in May, to begin mapping the specific priorities, path, and strategies that are needed to reach the 2025 goal.
- g. Goal 2: To Enhance Care Quality and Efficiency

- i. The National Alzheimer's Plan calls for an additional \$6 million for health care provider education and outreach. \$2 million of this was made available in 2012, and \$4 million is proposed for fiscal year 2013.
- h. Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families
 - i. The aim is to alleviate the burden of the disease on Americans affected by it.
 - ii. The National Plan calls for \$10.5 million in additional support for Alzheimer's caregivers in 2013.
- i. Goal 4: Enhance Public Awareness and Engagement
 - i. The National Alzheimer's Plan also aims to improve general knowledge about the disease, reduce stigma, and promote early detection and diagnosis by calling for \$8.2 million to Enhance Public Awareness and Engagement.
 - ii. This breaks down as \$4 million in 2012, some of which has helped to create alzheimer's.gov, a new web site designed to increase public understanding of the disease and offer resources to those with Alzheimer's and their caregivers; and \$4.2 million for public awareness in 2013.
- j. Goal 5: Improve Data to Track Progress
 - i. The National Alzheimer's Plan looks to Improve Data to Track Progress in order to assess how we're doing in the fight against Alzheimer's disease. This goal includes provisions to:
 - 1. Monitor progress by improving data collection on Alzheimer's and its impact on Americans;
 - 2. Create accountability by designating a federal agency responsible for every action step in the National Alzheimer's Plan; and
 - 3. Evaluate the effectiveness of the National Alzheimer's Plan by updating it annually.
- k. Questions and Discussion regarding the National Plan
 - i. Dr. Salazar asked for more details regarding improving data collection. Rob noted that so far, this is an area where the jury is still out. The cognitive survey used in the annual wellness visit for Medicare could help drive this forward. Karin Larkin noted that existing surveys, such as the long term care or assisted living surveys should include targeted questions about Alzheimer's. This could give us a running start to expand current data elements.
 - ii. Cass Naugle noted that NAPA seems to be getting a foothold, due to accountability among agencies and players, as well as timeframes,

reporting on progress, etc. These are important take homes for this group. In the back of the national plan, there are actions for who will achieve it, how and when.

- iii. Alice Hedt asked about proposed dollars for public education and where funding goes. Rob noted they are appropriated in the Office of the Secretary at DHHS. Some funds are administered through the Administration on Aging. Larger campaigns are done through the CDC.
- iv. Alice Hedt referenced other states with council's and commissions. She asked Rob if there were any states that did a good job or if there is communication between councils. Rob replied that the Alzheimer's Association tried to spur some of this. He provided the council with a State Government and Alzheimer's disease handout that shows all state plans cross referenced by topic. Most states are in the plan creation phase. This handout can serve as a roadmap of who to reach out to.
- v. Senator Jones-Rodwell asked about best practices across the country. She noted that the Alzheimer's Association could try to facilitate this conversation. This is a topic (training guidelines) where there will be more action. The Association could assist with the dissemination of new curricula.
- vi. Rob brought up the Healthy Brain Initiative. What's of interest is the overall notion that much of the work in the public health area wasn't focused. The CDC mandate for Alzheimer's and dementia did not receive much attention. The Association will be encouraging work around these action steps. Cross-collaboration in this area is possible if there are areas where the council is already working.
- vii. Delegate Pena-Melnyk asked whether the Alzheimer's Association would be able to function like the National Conference of State Legislatures. An MPH student could be used to work on this. Data collection is needed to address funding. She challenged the association to find a way to share information and resources. All 50 states need to be lobbying the federal government on this issue, not just the Alzheimer's Association.
 - 1. Rob thanked the Delegate for her interest in this issue and indicated that he would talk with the state team about next steps. The National plan has a recommendation like this as well. If this could be helpful, a letter to the advisory council expressing support for this idea would be well received. The federal government will be updating national plan annually (they are updating it now).

2. Karin Lakin noted that states should be talking to one another when developing their plans.
- viii. Alice Hedt stated that we must make sure state groups know what is going on at the federal level.

IV. Break out into workgroups

- a. The Council discussed breaking into 5 workgroups using the crosswalk structure that was created by staff. After discussing the best way to break up, the council ultimately decided to break into 5 groups that corresponded to the 5 goals in the State Plan. A facilitator was identified for each workgroup.
 - i. Support prevention & early intervention (Facilitator – Dr. Mansbach)
 - ii. Enhance quality of care (Facilitator - Dr. Kimberly Johnston)
 - iii. Enhance supports for persons living with ADRD and their families (Facilitators - Suzanne Carbone)
 - iv. Enhance public awareness (Facilitator - Cynthia fields)
 - v. Improve data capacity to track progress (Facilitator – Cass Naugle)
- b. Workgroups were asked to assess what is in place to achieve their respective goal and where gaps are. Each workgroup was asked to identify data needs as well.
- c. The Council members were instructed to self-select workgroups to participate in. Workgroup facilitators were asked to follow up with Council staff after the meeting to advise on workgroup membership.

V. Presentation on Alzheimer's Disease (Dr. Onyike, Johns Hopkins University)

- a. Dr. Onyike noted that it was unclear if we can reverse memory loss. It must be identified early and current technologies are moving toward that. However, there are a lot of false positives using certain screening methods. (ol style="list-style-type: none;"> - i. Suzanne Carbone advised that people don't know when to bring up memory loss issues with the doctor. Dr. Mansbach advised that people with early symptoms go to community-based doctors. We need to disseminate information to these doctors. Primary care physicians don't have as much time as specialists for each case. Annual wellness visits may create an opportunity to address this.
- b. The Council was running out of time so Brian Hepburn asked Dr. Onyike to speak about pharmacology. Developed in 2003, there have been a lot of promising leads but nothing has happened. We have capacity to measure clinical change in trials; however there is debate on which instrument is best. The field wants to move away from symptom measures to measuring pathology. Pharmaceuticals

are based on treating symptoms not disease modification. We need to raise awareness about this problem.

- c. Dr. Salazar noted that he doesn't prescribe medication for dementia because it only works for 6 to 12 months for roughly half of patients. Medications have adverse side effects, such as nausea in elderly individuals. Discontinuing medication is a battle with the family as well. In his opinion, we don't have dementia drugs that address the main problem.
- d. Dr. Onyike noted that there is a small subset of people who see an immediate benefit from medication. Dr. Salazar is correct though, the majority doesn't see any change. The challenge is to minimize the use of pharmaceuticals.
- e. Dr. Loreck stated that the Cochran reviews aren't good.

VI. Other

- a. The Council adjourned at 4:00. Council members were encouraged to meet with their workgroups further to schedule meeting times and exchange contact information.